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## **Do adolescent patients have a right to be informed about fertility preservation options by virtue of the Convention on the Rights of the Child?**

### **Abstract**

The 1989 United Nations Convention on the Rights of the Child not only states that children should be heard in matters of their concern according to their age and maturity, but also that children should have a right to have access to information. However, when it comes to medical indications, a consensus has not been reached on whether parents should disclose healthcare complications to their adolescent child. Adolescent disclosure becomes even more controversial when related to non-lifesaving procedures. In the United States, one child in 285 children is diagnosed with cancer every year, but thanks to improvements in medicine, the likelihood of survival has dramatically improved. However, cancer treatments, such as chemotherapy and radiation, are likely to affect their fertility later in their lives. Preventive medicine offers procedures to prevent this issue. Yet, if parents decline either disclosure or discussions, adolescent patients will have this possibility denied. As demonstrated by articles that have shown the impact of infertility on sexual well-being and happiness in adults, these patients may experience depression, anxiety, and lower self-esteem at a higher rate. By virtue of Article 17 of the Convention on the Rights of the Child, this essay aims to investigate if adolescents have a right to obtain information, not only through mass media, but also from their parents when disclosure “aims at the promotion of his or her social, [...] well-being and physical and mental health” and if being informed is within their best interest taking into consideration their age and maturity.

### **Keywords**

Adolescent decision-making – parental informed consent – gonadotoxic cancer treatment – fertility preservation options – Convention on the Rights of the Child – American pediatric bioethics

## **Introduction**

Early detection and improved cancer treatments have made it possible for almost 80% of children diagnosed with cancer during childhood to recover and enter adulthood with good long-term survival.<sup>1</sup> However, most of the cancer treatments available, such as radiotherapy and chemotherapy, are gonadotoxic,<sup>2</sup> resulting in infertility in 50% to 70% of cancer survivors.<sup>3</sup> In response to this risk, preventive medical interventions can be performed before starting life-saving therapies in order to preserve future fertility. When the patient is a minor, parents are entitled to give consent for the procedure. In cases where parents do not want to share information fearing that they may increase the burden on their child, a consensus on whether the patient should be informed has not been reached. This essay investigates whether adolescent patients should know about their fertility risks before starting cancer treatments by virtue of the 1989 United Nations Convention on the Rights of the Child.

## **Fertility Preservation for Female Adolescents**

In the United States, one in 285 children under 20 years old is diagnosed with cancer.<sup>4</sup> According to Kinahan et al., the number of diagnoses reaches 15,000 each year.<sup>5</sup> Early detection and improved cancer treatments have made it possible for almost 80% of children diagnosed with cancer during childhood to recover and enter adulthood with long-term survival. However, medical interventions, such as chemotherapy and radiotherapy, might impair fertility in the future.<sup>6</sup> The risks of infertility depend on the type of cancer, its malignancy, its treatment, the age of the patient at the time of diagnosis, and at the time the patient attempts to achieve a pregnancy. Gonadotoxic treatments may affect the oocytes in the ovaries, leading to an inability to successfully conceive.<sup>7</sup> In response to this risk and to the potential negative impact of infertility on sexual well-being and happiness in adults, concerns about the effects of treatments on cancer survivors' quality of life have arisen.<sup>8</sup>

To circumvent possible adverse outcomes due to cancer treatments, oncofertility is an emerging field in medicine that aims to protect the reproductive system when exposed to gonadotoxic drugs.<sup>9</sup> Assisted reproductive endocrinology has made alternatives possible, such as oocytes, embryos, and ovarian tissue

cryopreservation. Although oocyte and embryo cryopreservation are standards of care for post-prepubertal patients, these procedures are not suitable for pre-adolescent patients. Embryo cryopreservation requires the use of sperm from a partner or a donor which is not appropriate for children. Oocyte cryopreservation is also not advisable. Both procedures require ovarian stimulation to retrieve oocytes, which may cause ovarian hyperstimulation syndrome and intra-abdominal bleeding.<sup>10</sup> Moreover, in order to retrieve oocytes, it is necessary to wait 10 to 14 days until the completion of therapy, which delays the initiation of treatment for the underlying disease.<sup>11</sup>

Consequently, the safest and more suitable option for prepubertal and adolescent patients remains to undergo ovarian tissue cryopreservation. This procedure requires the removal of either the entire or a portion of the ovary by laparoscopy or laparotomy, both minimally invasive surgeries. The tissue can be reimplanted into the abdomen to try to restore endogenous hormonal secretion and the possibility of achieving an assisted or unassisted pregnancy. It is worth noting that recently, the American Society for Reproductive Medicine has removed the experimental label on this procedure.<sup>12</sup>

Furthermore, physical and psychological consequences due to cancer treatment side effects highlight the importance of fertility preservation services. Cancer survivors report lower natural pregnancy rates due to follicle depletion and uterus damage, lower success in achieving a pregnancy, higher rates of preterm delivery, lower birth weight in infants, higher likelihood of cesarian deliveries, and higher risk of postpartum hemorrhage.<sup>13</sup> Gonadotoxic treatment in female patients may lead to premature menopause, impacting their overall quality of life.<sup>14</sup>

Moreover, survivor cancer patients have shown higher psychological consequences when dealing with fertility issues.<sup>15</sup> After gonadotoxic therapy, the risk of infertility potentially increases their psychological distress and decreases their sexual well-being and self-esteem.<sup>16</sup> Additionally, infertility not only is perceived as a social stigma that may affect life planning and personal identity,<sup>17</sup> but also it may affect approaches toward sexual relationships.<sup>18</sup> Infertility may cause tension in marriage, increasing feelings of guilt if enough information and social support lack.<sup>19</sup> Younger people may need to feel “normal,” by engaging in sexual relationships with their partners, trying to conceive while hiding their condition, or

they may feel comfortable not using protection which may result in unplanned pregnancies.<sup>20</sup> Consequently, a lack of adequate information about infertility may cause young adults and adolescent patients to suffer from a lower quality of life due to higher levels of stress, concerns, and negative psychological impacts. Encouraging conversations may help them deal with infertility as a first step toward its acceptance.<sup>21</sup>

However, despite the importance that oncofertility has gained in the past decades, discussing the likelihood of fertility impairment after cancer treatments has been deemed to be one of the most difficult areas of medical disclosure, due to the great uncertainty that surrounds the diagnosis.<sup>22</sup> The difficulty to appraise long-term consequences of gonadotoxic drugs increases when the cancer patient is a minor, not only because informing such patients may be complicated, but also because little is known about infertility as a side effect in younger patients. In pediatrics, discussions become more complex because cancer diagnoses are usually utterly unexpected. Adolescents may perceive them in a devastating way and sense the situation as a death sentence. Moreover, they may be less aware of potential infertility risks, may have a poor understanding of the consequences, and may have little access to fertility preservation services than adult patients.<sup>23</sup> Yet, fertility impairments may lead to severe psychological repercussions even in younger patients. Among them, women have reported higher levels of emotional distress due to infertility.<sup>24</sup>

According to recent research, young adults and adolescent patients are more likely to receive incomplete information or not be informed at all.<sup>25</sup> Additionally, when it comes to treating adolescents and young adults, survival interests may prevail. Patients, families, and healthcare providers may focus more on cancer treatments in the present, limiting their concerns regarding potential future infertility.<sup>26</sup> Yet, studies have pointed out that not receiving adequate information may lead them to misconceptions of the risks. Adolescents have reported fears that could have been prevented if they had been properly educated, such as medically groundless worries about transmitting genetic conditions to their offspring because of the gonadotoxic treatment they underwent.<sup>27</sup>

Nevertheless, although the American Academy of Pediatrics along with the American Society of Clinical Oncology and the American Society for Reproductive Medicine have suggested that conversations with young patients should always be carried out, “parents may seek to shield their children from

information about infertility, fearing either a burden of that information or a distressing response from their child or adolescent.”<sup>28</sup> Although 14 states have adopted so-called “mature minor” laws requiring doctors by law to evaluate the ability of the child to make autonomous and sound medical decisions, when such regulations have not been implemented “minors must bend to the wishes of their authorized surrogates, usually their parent(s).”<sup>29</sup> Healthcare providers may feel moral distress handling situations in which they have been requested to hide information. However, if the parents deny disclosure, their decision should be respected.<sup>30</sup>

The second part of this paper investigates whether the Convention on the Rights of the Child addresses access to information as a right of the child and whether it may be applied to this circumstance.

### **Adolescent Patients’ Right to Have Access to Information**

In November 1989, the United Nations opened for signature the Convention on the Rights of the Child. In February 1995, Madeline Albright, as the US Ambassador to the UN signed it, but the Convention was never ratified. Since its inception, every country in the world has adopted the Convention on the Rights of the Child except for the United States.<sup>31</sup> Although the ex-president Barack Obama has considered this an embarrassing failure, nothing has been done to change it.<sup>32</sup> In 1998, Kilbourne Susan stated in her article “The Wayward Americans: Why the USA Has Not Ratified the UN Convention on the Rights of the Child” that the document may undermine parental authority, implying that the rights of the children should prevail over those of the parents. This threat may be one of the reasons why the US has not ratified the Convention.<sup>33</sup> However, the Convention reflects most of the American values. The administrations of two ex-presidents—Ronald Reagan and George Bush—actively took part in writing 38 of its 41 articles. Moreover, despite not being legally binding, the Supreme Court has recognized its moral authority.<sup>34</sup> The Convention has been deemed to be one of the most comprehensive covenants of international human rights.<sup>35</sup>

In virtue of the Convention, “children” are defined as “every human being below the age of eighteen years unless under the law applicable to the child, majority is attained earlier.”<sup>36</sup> Although it has not been ratified, four of its main objectives have been widely supported by American pediatric bioethics, when

establishing principles that should drive clinical decision-making and guarantee the protection of children. These four main objectives include the principles of non-discrimination, of the child's best interest, of the child's survival and development, and of the child's participation, which are considered of utmost importance respectively as expressed in Articles 2, 3, 6, and 12 of the Convention. Such principles mirror those of justice, beneficence, nonmaleficence, and autonomy as they have been defined within the field of bioethics.<sup>37</sup> Consequently, the Convention grants children the right to have their needs met as full persons, who should not be considered passive subjects of their parents' wishes. On the contrary, they should be treated as rights-holders, while their parents as duty-bearers who are entitled to make decisions on behalf of their children taking their kids' best interests into pivotal consideration.<sup>38</sup>

Even though in court settings, the right to be heard has been widely recognized,<sup>39</sup> when it comes to decisions regarding medical issues, parents or guardians are still legally those who decide.<sup>40</sup> The philosophy—recognized by the Convention—that the family has a special role in society as a fundamental unit underpins the adherence to parental discretion.<sup>41</sup> However, the Convention may be interpreted as an alternative to this framework. According to some scholars, Article 12—which states that, “every child capable of forming a view is entitled to express that view and have it taken seriously in accordance with her or his age and maturity”<sup>42</sup>—challenges the power dynamics between adults and children in American society.<sup>43</sup> Indeed, the Convention deems children as moral agents, requiring the State to assure them the rights to freedom of expression, thought, conscience and religion, along with those to have access to information, to privacy, and to education despite parental authority.<sup>44</sup> However, if the State holds the prerogative to interfere in the parents' rights to choose how to protect and raise their own children, the integrity of American families may be undermined.<sup>45</sup> Parental authority is at risk of being reduced, and parents risk becoming mere trustees of their child's best interest,<sup>46</sup> compromising the promotion of diversity and pluralism.<sup>47</sup>

Nevertheless, it is worth noticing that the Convention is an international document that was written with the aim to be globally accepted. To be ratified by the greatest number of states, it must be open to interpretation to respect different values and perspectives shared by a wide variety of cultures.<sup>48</sup>

Specifically, in Article 3, the Convention endorses the best interests of the child as the principle that should justify any decision made on their behalf.<sup>49</sup> The Committee has, indeed, emphasized that, “Parents should fulfill their responsibilities while always acting in the best interest of the child, if necessary with the support of the State. Taking the child’s evolving capacity into account, parents and caregivers should nurture, protect and support children to grow and develop in a healthy manner.”<sup>50</sup> Parents should take into consideration their child’s view in accordance with their maturity, and a case-by-case evaluation should be prioritized when conflicts between children and parents arise.<sup>51</sup> In 2002, the 27<sup>th</sup> Special Session of the United Nations General Assembly on children’s participation encouraged States to implement children’s, and specifically adolescents’, involvement in clinical decision-making. In this light, Article 12—that guarantees children to be able to express their views—and Article 17—that states that, “the child has access to information and material from a diversity of national and international sources, especially those aimed at the promotion of his or her social, spiritual and moral well-being and physical and mental health”<sup>52</sup>—should together be recognized as principles that drive toward a full application of the best interests of the child.<sup>53</sup>

When it comes to fertility preservation, the American Academy of Pediatrics has recommended that physicians should discuss the risk of fertility impairment due to cancer treatment and the availability of medical treatments to preserve future fertility.<sup>54</sup> Healthcare providers are called upon to discuss fertility preservation options in pediatric and adolescent cancer patients. They should offer consultations regardless of the cancer diagnosis, the cost of the procedure, and the family’s religion. When the patient is a child, the counseling about treatment, timing, and scope should be referred to a multidisciplinary team for a comprehensive approach to be applied to that specific child. It should be taken into account that decisions are made in a situation of stress after the disclosure of a life-threatening condition and must be made quickly since cancer treatment often requires to be started immediately. Thus, the type, stage, and severity of the diagnosis might affect the decision process. If possible, it is better to provide information about fertility preservation options in more than one meeting to give them time to comprehend the situation and to avoid



giving them false expectations.<sup>55</sup> Counselors should factor in families' cultures, religions, races, languages, health literacy, and cognitive levels.<sup>56</sup>

Therefore, the application of Article 17 of the Convention seems to align with the American societies' recommendations. The Committee of the CRC clarified that the views of the child should be assessed on a case-by-case basis. States shall ensure that children are heard regardless of their age. Setting an age limit regarding children's participation should be discouraged because their brain and cognitive maturation varies depending on the child.<sup>57</sup> Indeed, one of the reasons for why children are not involved in the decision making is that they lack capacity to do so for themselves. "Capacity" is defined as the ability to understand the medical facts, prognosis, the implications of suggested care and alternatives, including the risks and benefits of each option. They must be able to provide a reasonable explanation for the decision made based on their own beliefs, values, and goals.<sup>58</sup> Yet, assessing capacity remains complicated since it "falls along a continuum, with no natural threshold [to set its adequacy]."<sup>59</sup> Regardless of the definition, medical communities generally agree that children are not deemed to have decision-making capacity, because their cognitive abilities are not fully developed.<sup>60</sup> Still, the ability to understand the short- and long-term consequences of medical procedures vary not only depending on the situation, but also depending on the personal socioemotional maturity.

Neurodevelopmental research has demonstrated that decisions may be hampered "by the relatively slow growth and maturation of the prefrontal cortex."<sup>61</sup> However, when it comes to adolescents, studies have shown that they may be able to understand and appreciate the situation. Even though brain development continues into adulthood, their ability to discern and make decisions can be achieved in their mid-teen years. Studies have reported that capacity in minors aged 14 and older statistically does not differ greatly from capacity in adults. Yet, capacity assessments may vary depending on the complexity of the situation.<sup>62</sup> Nevertheless, it has been demonstrated that, regardless of being able to fully comprehend, their emotional state may influence their decision. Researchers have distinguished between hot and cold cognition. With hot cognition, adolescents are deemed to have fewer skills in handling situations where high levels of emotion lead them to make decisions out of impulsivity. In contrast, with cold cognition,

adolescents handle less-stressful situations when they have time to reason.<sup>63</sup> Having conversations with them may improve their ability to assess the circumstance, fostering their involvement in the decision-making process. However, although the Maine Supreme Court has recognized that “capacity exists when the minor has the ability of the average person to understand and weigh the risks and benefits,”<sup>64</sup> a consensus as to whether adolescents should be deemed able to make decisions and be informed has not been reached.<sup>65</sup>

## **Conclusions**

The purpose of this essay was to investigate whether children, and more specifically adolescents, have a right to have access to information about fertility preservation options. These non-life-saving procedures may prevent them from infertility later in their lives due to gonadotoxic treatments provided against their cancer diagnosis. Studies have demonstrated that infertility can reduce the overall quality of life of cancer survivors. A lack of information may increase anxiety and fears even in younger patients, leading them to misconceptions about their condition. Nevertheless, despite American societies having recommended discussing fertility preservation options, adolescents still may not receive counseling.

Children’s perspectives have been widely undermined where their parents’ voices have prevailed.<sup>66</sup> The 1989 UN Convention on the Rights of the Child and the 27<sup>th</sup> Special Session of the United Nations General Assembly have tried to promote a new framework to include children and adolescents in the decision-making process.<sup>67</sup> Therefore, programs that encourage mutual respect between parents and their children should be implemented taking into consideration their maturity and evolving capacities,<sup>68</sup> especially bearing in mind the psychological distress likely to follow a diagnosis of infertility.

Allowing children and adolescents to express their opinions and be aware of the benefits and burdens of the treatments they need to undergo may increase their overall psychological and physical well-being. Studies have demonstrated that participation in clinical decision-making increases levels of satisfaction with the care received, diminishes fears, and encourages preparedness.<sup>69</sup> It is of utmost importance to take into consideration that children and adolescents “have a critical role to play in their own care and well-being.”<sup>70</sup> Therefore, when making decisions in light of the best interests of the child, we

should not forget the importance of allowing adolescent patients to have access to information and to express their views as it has been recommended by the Convention on the Rights of the Child.

## Endnotes

<sup>1</sup>K. E. Dillon and C. R. Gracia, "Pediatric and young adult patients and oncofertility," *Curr Treat Options Oncol* 13, no. 2 (2012), <https://doi.org/10.1007/s11864-012-0183-7>; S. Klipstein, M. E. Fallat, and S. Savelli, "Fertility Preservation for Pediatric and Adolescent Patients With Cancer: Medical and Ethical Considerations," *Pediatrics* 145, no. 3 (2020), <https://doi.org/10.1542/peds.2019-3994>.

<sup>2</sup>N. A. Deshpande, I. M. Braun, and F. L. Meyer, "Impact of fertility preservation counseling and treatment on psychological outcomes among women with cancer: A systematic review," *Cancer* 121, no. 22 (2015), <https://doi.org/10.1002/cncr.29637>; Klipstein, Fallat, and Savelli, "Fertility Preservation for Pediatric and Adolescent Patients With Cancer: Medical and Ethical Considerations."

<sup>3</sup>P. Patterson et al., "Infertility After Cancer: How the Need to Be a Parent, Fertility-Related Social Concern, and Acceptance of Illness Influence Quality of Life," *Cancer Nurs* 44, no. 4 (2021), <https://doi.org/10.1097/ncc.0000000000000811>.

<sup>4</sup>Klipstein, Fallat, and Savelli, "Fertility Preservation for Pediatric and Adolescent Patients With Cancer: Medical and Ethical Considerations."

<sup>5</sup>K. Kinahan, Boots, C, and Didwania, A, "Childhood, Adolescent, and Young Adult Cancer: Fertility Implications and Clinical Practice," in *Textbook of Oncofertility Research and Practice*, ed. Divya K. Shah Teresa K. Woodruff, and Wendy S. Vitek (Switzerland: Springer Nature, 2019).

<sup>6</sup>Deshpande, Braun, and Meyer, "Impact of fertility preservation counseling and treatment on psychological outcomes among women with cancer: A systematic review."; L. Lotz et al., "The safety and satisfaction of ovarian tissue cryopreservation in prepubertal and adolescent girls," *Reprod Biomed Online* 40, no. 4 (2020), <https://doi.org/10.1016/j.rbmo.2020.01.009>; M. J. Griffiths, A. L. Winship, and K. J. Hutt, "Do cancer therapies damage the uterus and compromise fertility?," *Hum Reprod Update* 26, no. 2 (2020), <https://doi.org/10.1093/humupd/dmz041>; Dillon and Gracia, "Pediatric and young adult patients and oncofertility."

<sup>7</sup>Klipstein, Fallat, and Savelli, "Fertility Preservation for Pediatric and Adolescent Patients With Cancer: Medical and Ethical Considerations."; M. Lambertini et al., "Cancer and fertility preservation: international recommendations from an expert meeting," *BMC Med* 14 (2016), <https://doi.org/10.1186/s12916-015-0545-7>.

<sup>8</sup>Lotz et al., "The safety and satisfaction of ovarian tissue cryopreservation in prepubertal and adolescent girls."; C. Poirot et al., "Ovarian tissue cryopreservation for fertility preservation in 418 girls and adolescents up to 15 years of age facing highly gonadotoxic treatment. Twenty years of experience at a single center," *Acta Obstet Gynecol Scand* 98, no. 5 (2019), <https://doi.org/10.1111/aogs.13616>; R. J. McDougall et al., "Ethics of fertility preservation for prepubertal children: should clinicians offer procedures where efficacy is largely unproven?," *J Med Ethics* 44, no. 1 (2018), <https://doi.org/10.1136/medethics-2016-104042>; A. Linkeviciute, and Peccatori, F. A., "Oncofertility," in *Ethical Counseling and Medical Decision-Making in the Era of Personalized Medicine. A practice-oriented Guide*, ed. Sanchini V. Boniolo G. (Switzerland: Springer, 2016).

<sup>9</sup>Griffiths, Winship, and Hutt, "Do cancer therapies damage the uterus and compromise fertility?."

<sup>10</sup>P. Kumar et al., "Ovarian hyperstimulation syndrome," *J Hum Reprod Sci* 4, no. 2 (2011), <https://doi.org/10.4103/0974-1208.86080>.

<sup>11</sup>K. McCracken and L. Nahata, "Fertility preservation in children and adolescents: current options and considerations," *Curr Opin Obstet Gynecol* 29, no. 5 (2017), <https://doi.org/10.1097/gco.0000000000000395>.

<sup>12</sup>K. Hinkle et al., "Cryopreservation of Ovarian Tissue for Pediatric Fertility," *Biopreserv Biobank* 19, no. 2 (2021), <https://doi.org/10.1089/bio.2020.0124>.

<sup>13</sup>Lambertini et al., "Cancer and fertility preservation: international recommendations from an expert meeting."; Griffiths, Winship, and Hutt, "Do cancer therapies damage the uterus and compromise fertility?."

<sup>14</sup>M. A. Crawshaw and P. Sloper, "'Swimming against the tide'--the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer," *Eur J Cancer Care (Engl)* 19, no. 5 (2010), <https://doi.org/10.1111/j.1365-2354.2009.01118.x>.

<sup>15</sup>Lambertini et al., "Cancer and fertility preservation: international recommendations from an expert meeting."

<sup>16</sup>McDougall et al., "Ethics of fertility preservation for prepubertal children: should clinicians offer procedures where efficacy is largely unproven?."

- <sup>17</sup> M. A. Crawshaw et al., "Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years," *Eur J Cancer Care (Engl)* 18, no. 4 (2009), <https://doi.org/10.1111/j.1365-2354.2008.01003.x>; Crawshaw and Sloper, "'Swimming against the tide'--the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer."; Patterson et al., "Infertility After Cancer: How the Need to Be a Parent, Fertility-Related Social Concern, and Acceptance of Illness Influence Quality of Life."
- <sup>18</sup> Crawshaw and Sloper, "'Swimming against the tide'--the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer."; Patterson et al., "Infertility After Cancer: How the Need to Be a Parent, Fertility-Related Social Concern, and Acceptance of Illness Influence Quality of Life."; B. J. Zebrack et al., "Fertility issues for young adult survivors of childhood cancer," *Psychooncology* 13, no. 10 (2004), <https://doi.org/10.1002/pon.784>.
- <sup>19</sup> Zebrack et al., "Fertility issues for young adult survivors of childhood cancer."
- <sup>20</sup> Zebrack et al., "Fertility issues for young adult survivors of childhood cancer."; Crawshaw and Sloper, "'Swimming against the tide'--the influence of fertility matters on the transition to adulthood or survivorship following adolescent cancer."
- <sup>21</sup> Patterson et al., "Infertility After Cancer: How the Need to Be a Parent, Fertility-Related Social Concern, and Acceptance of Illness Influence Quality of Life."
- <sup>22</sup> Crawshaw et al., "Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years."
- <sup>23</sup> Crawshaw et al., "Male and female experiences of having fertility matters raised alongside a cancer diagnosis during the teenage and young adult years."; T. Sandheinrich et al., "Knowledge and perceptions of infertility in female cancer survivors and their parents," *Support Care Cancer* 26, no. 7 (2018), <https://doi.org/10.1007/s00520-018-4080-x>.
- <sup>24</sup> Sandheinrich et al., "Knowledge and perceptions of infertility in female cancer survivors and their parents."
- <sup>25</sup> Deshpande, Braun, and Meyer, "Impact of fertility preservation counseling and treatment on psychological outcomes among women with cancer: A systematic review."
- <sup>26</sup> Sandheinrich et al., "Knowledge and perceptions of infertility in female cancer survivors and their parents."
- <sup>27</sup> Zebrack et al., "Fertility issues for young adult survivors of childhood cancer."
- <sup>28</sup> Zebrack et al., "Fertility issues for young adult survivors of childhood cancer."
- <sup>29</sup> P. M. Rosoff, "Do Pediatric Patients Have a Right to Know?," *AMA J Ethics* 19, no. 5 (2017), <https://doi.org/10.1001/journalofethics.2017.19.5.ecas2-1705>.
- <sup>30</sup> Rosoff, "Do Pediatric Patients Have a Right to Know?."
- <sup>31</sup> G. Lansdown, L. Lundy, and J. Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics," *Perspect Biol Med* 58, no. 3 (2016), <https://doi.org/10.1353/pbm.2016.0005>; J. Todres and A. Diaz, "Adolescents' Right to Participate: Opportunities and Challenges for Health Care Professionals," *Ann Glob Health* 83, no. 5-6 (2017), <https://doi.org/10.1016/j.aogh.2017.10.019>; P. A. Michaud et al., "Assessing an Adolescent's Capacity for Autonomous Decision-Making in Clinical Care," *J Adolesc Health* 57, no. 4 (2015), <https://doi.org/10.1016/j.jadohealth.2015.06.012>.
- <sup>32</sup> Michaud et al., "Assessing an Adolescent's Capacity for Autonomous Decision-Making in Clinical Care."
- <sup>33</sup> Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics."
- <sup>34</sup> K. R. Lang and C. D. Lew, "Actions Speak Louder Than Words: The U.N. Convention on the Rights of the Child and U.S. Pediatric Bioethicists," *Perspect Biol Med* 58, no. 3 (2016), <https://doi.org/10.1353/pbm.2016.0010>.
- <sup>35</sup> Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics."
- <sup>36</sup> General Assembly United Nation, *Convention on the Rights of the Child* (New York, 1989).
- <sup>37</sup> Lang and Lew, "Actions Speak Louder Than Words: The U.N. Convention on the Rights of the Child and U.S. Pediatric Bioethicists."; J. Goldhagen et al., "Toward a Child Rights Theory in Pediatric Bioethics," *Perspect Biol Med* 58, no. 3 (2016), <https://doi.org/10.1353/pbm.2016.0014>. Committee on the Rights of the Child United Nation, *General Comment No. 12: The right of the child to be heard* (Geneva, 1 July 2009 2009).
- <sup>38</sup> Goldhagen et al., "Toward a Child Rights Theory in Pediatric Bioethics."; Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics."; J. Goldhagen, "Following the Yellow Brick Road: Next Steps in the Synthesis of Pediatric Bioethics and Child Rights," *Perspect Biol Med* 58, no. 3 (2016), <https://doi.org/10.1353/pbm.2016.0006>.
- <sup>39</sup> Todres and Diaz, "Adolescents' Right to Participate: Opportunities and Challenges for Health Care Professionals."

- <sup>40</sup> L. A. Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?," *Pediatrics* 146, no. Suppl 1 (2020), <https://doi.org/10.1542/peds.2020-0818G>.
- <sup>41</sup> Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?."; A. S. Iltis, "Toward a coherent account of pediatric decision making," *J Med Philos* 35, no. 5 (2010), <https://doi.org/10.1093/jmp/jhq039>.
- <sup>42</sup> Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics."
- <sup>43</sup> C. Davies, J. Fraser, and D. Waters, "Establishing a framework for listening to children in healthcare," *J Child Health Care* (2019), <https://doi.org/10.1177/1367493519872078>.
- <sup>44</sup> M. J. Cherry, "Parental authority and pediatric bioethical decision making," *J Med Philos* 35, no. 5 (2010), <https://doi.org/10.1093/jmp/jhq043>.
- <sup>45</sup> Iltis, "Toward a coherent account of pediatric decision making."
- <sup>46</sup> H. T. Engelhardt, Jr., "Beyond the best interests of children: four views of the family and of foundational disagreements regarding pediatric decision making," *J Med Philos* 35, no. 5 (2010), <https://doi.org/10.1093/jmp/jhq042>; Cherry, "Parental authority and pediatric bioethical decision making."
- <sup>47</sup> Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?."
- <sup>48</sup> Iltis, "Toward a coherent account of pediatric decision making."
- <sup>49</sup> Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?."; Cherry, "Parental authority and pediatric bioethical decision making."; Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics."; Goldhagen et al., "Toward a Child Rights Theory in Pediatric Bioethics."; United Nation, *General Comment No. 12: The right of the child to be heard*
- <sup>50</sup> Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics."
- <sup>51</sup> Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics."
- <sup>52</sup> United Nation, *Convention on the Rights of the Child*.
- <sup>53</sup> Lansdown, Lundy, and Goldhagen, "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics." United Nation, *General Comment No. 12: The right of the child to be heard*
- <sup>54</sup> Corkum et al., "Fertility and hormone preservation and restoration for female children and adolescents receiving gonadotoxic cancer treatments: A systematic review."
- <sup>55</sup> Klipstein, Fallat, and Savelli, "Fertility Preservation for Pediatric and Adolescent Patients With Cancer: Medical and Ethical Considerations."
- <sup>56</sup> Kinahan, "Childhood, Adolescent, and Young Adult Cancer: Fertility Implications and Clinical Practice."
- <sup>57</sup> United Nation, *General Comment No. 12: The right of the child to be heard*
- <sup>58</sup> Bernard Lo, "Decision-Making Capacity," in *Resolving Ethical Dilemmas. A Guide for Clinicians* (Philadelphia Lippincott, Williams & Wilkins, 2020).
- <sup>59</sup> Lo, "Decision-Making Capacity."
- <sup>60</sup> E. De Clercq et al., "'Undoing' Capacity: The Capability Approach in Pediatrics," *Perspect Biol Med* 62, no. 2 (2019), <https://doi.org/10.1353/pbm.2019.0016>.
- <sup>61</sup> Michaud et al., "Assessing an Adolescent's Capacity for Autonomous Decision-Making in Clinical Care."
- <sup>62</sup> Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?."
- <sup>63</sup> Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?."
- <sup>64</sup> Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?."
- <sup>65</sup> Weithorn, "When Does A Minor's Legal Competence To Make Health Care Decisions Matter?."
- <sup>66</sup> Davies, Fraser, and Waters, "Establishing a framework for listening to children in healthcare."
- <sup>67</sup> M. Söderbäck, I. Coyne, and M. Harder, "The importance of including both a child perspective and the child's perspective within health care settings to provide truly child-centred care," *J Child Health Care* 15, no. 2 (2011), <https://doi.org/10.1177/1367493510397624>; United Nation, *General Comment No. 12: The right of the child to be heard*
- <sup>68</sup> United Nation, *General Comment No. 12: The right of the child to be heard*
- <sup>69</sup> I. Coyne et al., "Interventions for promoting participation in shared decision-making for children with cancer," *Cochrane Database Syst Rev* 11, no. 11 (2016), <https://doi.org/10.1002/14651858.CD008970.pub3>.
- <sup>70</sup> Todres and Diaz, "Adolescents' Right to Participate: Opportunities and Challenges for Health Care Professionals."

## Bibliography

- 
- Cherry, M. J. "Parental Authority and Pediatric Bioethical Decision Making." *J Med Philos* 35, no. 5 (2010): 553-72. <https://doi.org/10.1093/jmp/jhq043>.
- Corkum, K. S., D. S. Rhee, Q. E. Wafford, I. Demeestere, R. Dasgupta, R. Baertschiger, M. M. Malek, *et al.* "Fertility and Hormone Preservation and Restoration for Female Children and Adolescents Receiving Gonadotoxic Cancer Treatments: A Systematic Review." *J Pediatr Surg* 54, no. 11 (2019): 2200-09. <https://doi.org/10.1016/j.jpedsurg.2018.12.021>.
- Coyne, I., I. Hallström, and M. Söderbäck. "Reframing the Focus from a Family-Centred to a Child-Centred Care Approach for Children's Healthcare." *J Child Health Care* 20, no. 4 (2016): 494-502. <https://doi.org/10.1177/1367493516642744>.
- Coyne, I., D. P. O'Mathúna, F. Gibson, L. Shields, E. Leclercq, and G. Sheaf. "Interventions for Promoting Participation in Shared Decision-Making for Children with Cancer." *Cochrane Database Syst Rev* 11, no. 11 (2016). <https://doi.org/10.1002/14651858.CD008970.pub3>.
- Crawshaw, M. A., A. W. Glaser, J. P. Hale, and P. Sloper. "Male and Female Experiences of Having Fertility Matters Raised Alongside a Cancer Diagnosis During the Teenage and Young Adult Years." *Eur J Cancer Care (Engl)* 18, no. 4 (2009): 381-90. <https://doi.org/10.1111/j.1365-2354.2008.01003.x>.
- Crawshaw, M. A., and P. Sloper. "Swimming against the Tide"--the Influence of Fertility Matters on the Transition to Adulthood or Survivorship Following Adolescent Cancer." *Eur J Cancer Care (Engl)* 19, no. 5 (2010): 610-20. <https://doi.org/10.1111/j.1365-2354.2009.01118.x>.
- Davies, C., J. Fraser, and D. Waters. "Establishing a Framework for Listening to Children in Healthcare." *J Child Health Care* (2019). <https://doi.org/10.1177/1367493519872078>.
- De Clercq, E., J. Streuli, K. Ruhe, and B. S. Elger. "'Undoing' Capacity: The Capability Approach in Pediatrics." *Perspect Biol Med* 62, no. 2 (2019): 319-36. <https://doi.org/10.1353/pbm.2019.0016>.
- Deshpande, N. A., I. M. Braun, and F. L. Meyer. "Impact of Fertility Preservation Counseling and Treatment on Psychological Outcomes among Women with Cancer: A Systematic Review." *Cancer* 121, no. 22 (2015): 3938-47. <https://doi.org/10.1002/cncr.29637>.
- Dillon, K. E., and C. R. Gracia. "Pediatric and Young Adult Patients and Oncofertility." *Curr Treat Options Oncol* 13, no. 2 (2012): 161-73. <https://doi.org/10.1007/s11864-012-0183-7>.
- Engelhardt, H. T., Jr. "Beyond the Best Interests of Children: Four Views of the Family and of Foundational Disagreements Regarding Pediatric Decision Making." *J Med Philos* 35, no. 5 (2010): 499-517. <https://doi.org/10.1093/jmp/jhq042>.
- Goldhagen, J. "Following the Yellow Brick Road: Next Steps in the Synthesis of Pediatric Bioethics and Child Rights." *Perspect Biol Med* 58, no. 3 (2016): 365-75. <https://doi.org/10.1353/pbm.2016.0006>.
- Goldhagen, J., R. Mercer, E. Webb, R. Nathawad, S. Shenoda, and G. Lansdown. "Toward a Child Rights Theory in Pediatric Bioethics." *Perspect Biol Med* 58, no. 3 (2016): 306-19. <https://doi.org/10.1353/pbm.2016.0014>.
- Griffiths, M. J., A. L. Winship, and K. J. Hutt. "Do Cancer Therapies Damage the Uterus and Compromise Fertility?." *Hum Reprod Update* 26, no. 2 (2020): 161-73. <https://doi.org/10.1093/humupd/dmz041>.
- Hinkle, K., K. E. Orwig, H. Valli-Pulaski, S. Taylor, K. van Leeuwen, D. Carpentieri, and A. Walsh. "Cryopreservation of Ovarian Tissue for Pediatric Fertility." *Biopreserv Biobank* 19, no. 2 (2021): 130-35. <https://doi.org/10.1089/bio.2020.0124>.
- Iltis, A. S. "Toward a Coherent Account of Pediatric Decision Making." *J Med Philos* 35, no. 5 (2010): 526-52. <https://doi.org/10.1093/jmp/jhq039>.
- Kinahan, K., Boots, C., and Didwania, A. "Childhood, Adolescent, and Young Adult Cancer: Fertility Implications and Clinical Practice." In *Textbook of Oncofertility Research and Practice*, edited by Divya K. Shah Teresa K. Woodruff, and Wendy S. Vitek, 15-27. Switzerland: Springer Nature, 2019.
- Klipstein, S., M. E. Fallat, and S. Savelli. "Fertility Preservation for Pediatric and Adolescent Patients with Cancer: Medical and Ethical Considerations." *Pediatrics* 145, no. 3 (2020): 1-19. <https://doi.org/10.1542/peds.2019-3994>.
- Kumar, P., S. F. Sait, A. Sharma, and M. Kumar. "Ovarian Hyperstimulation Syndrome." *J Hum Reprod Sci* 4, no. 2 (2011): 70-5. <https://doi.org/10.4103/0974-1208.86080>.
- Lambertini, M., L. Del Mastro, M. C. Pescio, C. Y. Andersen, H. A. Azim, Jr., F. A. Peccatori, M. Costa, *et al.* "Cancer and Fertility Preservation: International Recommendations from an Expert Meeting." *BMC Med* 14 (2016): 1. <https://doi.org/10.1186/s12916-015-0545-7>.
- Lang, K. R., and C. D. Lew. "Actions Speak Louder Than Words: The U.N. Convention on the Rights of the Child and U.S. Pediatric Bioethicists." *Perspect Biol Med* 58, no. 3 (2016): 281-9. <https://doi.org/10.1353/pbm.2016.0010>.

- 
- Lansdown, G., L. Lundy, and J. Goldhagen. "The U.N. Convention on the Rights of the Child: Relevance and Application to Pediatric Clinical Bioethics." *Perspect Biol Med* 58, no. 3 (2016): 252-66. <https://doi.org/10.1353/pbm.2016.0005>.
- Linkeviciute, A., and Peccatori, F. A. "Oncofertility." In *Ethical Counseling and Medical Decision-Making in the Era of Personalized Medicine. A Practice-Oriented Guide*, edited by Sanchini V. Boniolo G., 97-104. Switzerland: Springer, 2016.
- Lo, Bernard. "Decision-Making Capacity." In *Resolving Ethical Dilemmas. A Guide for Clinicians* 67-76. Philadelphia Lippincott, Williams & Wilkins, 2020.
- Lotz, L., P. R. Barbosa, C. Knorr, L. Hofbeck, I. Hoffmann, M. W. Beckmann, S. Antoniadis, and R. Dittrich. "The Safety and Satisfaction of Ovarian Tissue Cryopreservation in Prepubertal and Adolescent Girls." *Reprod Biomed Online* 40, no. 4 (2020): 547-54. <https://doi.org/10.1016/j.rbmo.2020.01.009>.
- McCracken, K., and L. Nahata. "Fertility Preservation in Children and Adolescents: Current Options and Considerations." *Curr Opin Obstet Gynecol* 29, no. 5 (2017): 283-88. <https://doi.org/10.1097/gco.0000000000000395>.
- McDougall, R. J., L. Gillam, C. Delany, and Y. Jayasinghe. "Ethics of Fertility Preservation for Prepubertal Children: Should Clinicians Offer Procedures Where Efficacy Is Largely Unproven?". *J Med Ethics* 44, no. 1 (2018): 27-31. <https://doi.org/10.1136/medethics-2016-104042>.
- Michaud, P. A., R. W. Blum, L. Benaroyo, J. Zermatten, and V. Baltag. "Assessing an Adolescent's Capacity for Autonomous Decision-Making in Clinical Care." *J Adolesc Health* 57, no. 4 (2015): 361-6. <https://doi.org/10.1016/j.jadohealth.2015.06.012>.
- Patterson, P., J. Perz, R. Tindle, F. E. J. McDonald, and J. M. Ussher. "Infertility after Cancer: How the Need to Be a Parent, Fertility-Related Social Concern, and Acceptance of Illness Influence Quality of Life." *Cancer Nurs* 44, no. 4 (2021): E244-e51. <https://doi.org/10.1097/ncc.0000000000000811>.
- Poirot, C., L. Brugieres, K. Yakouben, M. Prades-Borio, F. Marzouk, G. de Lambert, H. Pacquement, *et al*. "Ovarian Tissue Cryopreservation for Fertility Preservation in 418 Girls and Adolescents up to 15 years of Age Facing Highly Gonadotoxic Treatment. Twenty Years of Experience at a Single Center." *Acta Obstet Gynecol Scand* 98, no. 5 (2019): 630-37. <https://doi.org/10.1111/aogs.13616>.
- Rosoff, P. M. "Do Pediatric Patients Have a Right to Know?". *AMA J Ethics* 19, no. 5 (2017): 426-35. <https://doi.org/10.1001/journalofethics.2017.19.5.ecas2-1705>.
- Sandheinrich, T., S. B. Wondmeneh, C. Mohrmann, K. Gettinger, J. Henry, and R. J. Hayashi. "Knowledge and Perceptions of Infertility in Female Cancer Survivors and Their Parents." *Support Care Cancer* 26, no. 7 (2018): 2433-39. <https://doi.org/10.1007/s00520-018-4080-x>.
- Söderbäck, M., I. Coyne, and M. Harder. "The Importance of Including Both a Child Perspective and the Child's Perspective within Health Care Settings to Provide Truly Child-Centred Care." *J Child Health Care* 15, no. 2 (2011): 99-106. <https://doi.org/10.1177/1367493510397624>.
- Todres, J., and A. Diaz. "Adolescents' Right to Participate: Opportunities and Challenges for Health Care Professionals." *Ann Glob Health* 83, no. 5-6 (2017): 697-703. <https://doi.org/10.1016/j.aogh.2017.10.019>.
- United Nation, Committee on the Rights of the Child *General Comment No. 12: The Right of the Child to Be Heard* (Geneva: 1 July 2009 2009).
- United Nation, General Assembly *Convention on the Rights of the Child*. (New York: 1989).
- Weithorn, L. A. "When Does a Minor's Legal Competence to Make Health Care Decisions Matter?". *Pediatrics* 146, no. Suppl 1 (2020): S25-s32. <https://doi.org/10.1542/peds.2020-0818G>.
- Zebrack, B. J., J. Casillas, L. Nohr, H. Adams, and L. K. Zeltzer. "Fertility Issues for Young Adult Survivors of Childhood Cancer." *Psychooncology* 13, no. 10 (2004): 689-99. <https://doi.org/10.1002/pon.784>.